HSP Newslink

The Newsletter of the Hereditary Spastic Paraplegia Support Group

Issue 54 – October 2022

HSP & FSP – Hereditary Spastic Paraplegia,
Familial Spastic Paraplegia & Strumpell-Lorrain Syndrome

Estelle's Marathon Challenge for HSP

Estelle and her dad Michael following a training run

I have always aspired to run in the London Marathon and I have entered the ballot for the past 7 years. Finally this year I got a place and it really is a dream come true. I am taking the opportunity to raise money for the HSP Support Group, of which my dad is a member, having been diagnosed with the disorder 9 years ago.

I have been following the 17 week London Marathon Advanced Training Programme which means training 5 times a week with a long run every Sunday. My latest long run was 18 miles. The maximum I will run in training is 22 miles in a few weeks' time before running the full 26.2 miles on Sunday 2nd October! I have really loved the training even though it has meant some very early mornings so that it doesn't impact family life too much. I have a 3-year-old son and a 1 year old daughter who also require my attention!

My children, Jonas and Heidi, are 2 of my parents' 9 grandchildren ranging from ages 7 (twins) to just 4 months old! I suppose a large number of grandchildren is no surprise given that my parents had 7 children themselves. I am the 2nd youngest and it is fair to say we kept my parents extremely busy for many many years and they in turn kept us very busy.

For as long as I can remember my parents, Michael and Lorraine Bradley, have loved an active lifestyle, which has included swimming, cycling and regular gym sessions. They were first introduced to one another in church after a service, by a mutual friend who was part of the Ramblers Club in Liverpool which my dad was also a member of. As a family we spent our summer holidays caravanning in the UK, going on 25 mile cycle rides each day and we spent our October half terms in the Lake District being coaxed up mountains with Kendal Mint Cake! When I decided to take up running, in order to train for a 6 mile race at school, my dad would get up with me early in the morning and keep me company, along with my mom. They continued to run together long after I went to University.

My parents' dream for retirement was a simple one - to be able to walk the coastal paths of England together. However, unfortunately this has not been possible. My mom had always noticed that my dad had a slightly strange gait and a shuffle when he walked and as this slowly became more prominent, he was diagnosed with HSP. Over the years my dad's mobility has deteriorated but he has and continues to fight it as best he can. When he could no longer run with my mom, he instead cycled beside her. Now that he can no longer cycle, he uses a rollator in order to aid his walking and does his exercise in a seated position on a chair, following ' Hasfit for seniors' on YouTube. I have not heard him complain once about having this disorder even though it has taken away one of the greatest pleasures he has known in life - being active. He continues to have a smile on his face and is a one in a million father and grandfather.

Being able to run the London Marathon is a dream come true for me and I realise how lucky I am to physically be able to do so, something I don't take for granted. On my long training runs when it is difficult, I think about my dad and everyone else that also suffers from mobility issues and the impact it has on those, like my mom, who love and care for them on a daily basis, and it absolutely spurs me on. I am raising money for the HSP Support Group so that it can continue to support its members and undertake the important research that it does. If anyone is able to and would like to donate, I have a Just Giving page which is linked below:

https://www.justgiving.com/fundraising/Estelle-Hetherington

A huge thank you to anyone who has donated so far.

Many thanks

Estelle Hetherington

Estelle has already raised an amazing £ 1,300. Good luck for your run and many thanks for your efforts

Chairman's Column

Hello

Hello to all our members and others reading. I'm writing this column in the week after the passing of Her Majesty Queen Elizabeth II. It feels like quite an important moment in history. The Queen was patron for many charities, including many for those with disabilities and heath conditions. I remember the intense sadness and grief when my father died in 2005, and I can only imagine how the royal family are dealing with their grief in the public eye. I think that the Queen made such an important contribution to the world, and I send my most sincere condolences to the whole royal family.

Another major change since my last column is the lifting of coronavirus restrictions (at the end of February). This allowed us to get back things similarly to 2019 and early 2020. I'm still finding face coverings which I'd popped in bags and pockets, and am quite pleased not to have to use those. Of course, coronavirus is still out there, and I'm planning to take up the offer of my booster vaccine when it comes through. I encourage all to take care in their day-to-day activities.

One final date of note – I was looking through my filing system and note that Ian Bennett asked me to write and introduce myself back in 2012, so you've been reading things from me for 10 years!

Group Social – 8th October

Assuming that this newslink arrives with you in late September or early October, I'll take the opportunity to remind you about our upcoming group social at the Tally Ho conference centre in Birmingham on Sat 8th October. You should have all had by now more details of this event. The plan for the day is to have a few tables set up for people to join in specific conversations, whilst others

can just mingle and chat socially. We'll also have a few of our friends from the HSP research community who are happy to chat with you, and there will be an opportunity to 'show and tell' mobility equipment or other aids which you find particularly useful.

We decided on a social event as several commented over the years they prefer the more social interactions and fewer of the formal presentations. We want to see how this type of event works. I like being able to record our AGM and presentations and having them on our YouTube channel, available to watch at any time. I am pleased to note there is a steady stream of people watching our videos month on month.

AGM

Having mentioned the group social it also feels appropriate to cover our decision to stay with a virtual AGM this year. When planning the AGM, the coronavirus restrictions (which meant we could not be face-to-face in 2020 and 2021) were no longer in place, and we know that several of you enjoy the face-to-face social aspects of these meetings. However, we know that there are many members who have great difficulty travelling, either because of the distance or because of their level of mobility. By having the AGM virtually (and voting in advance) it is possible for anyone with an internet connection to take part in the AGM, and we felt that this was an important aspect.

I'd be very pleased to hear your views on this either way, so please send me an e-mail/letter or talk to me on the 8th October in Birmingham!

I have written summaries of the two presentations we had after the AGM which are elsewhere in this newsletter. You can, of course, watch these on our YouTube channel. https://www.youtube.com/channel/ukhspsupportgroup. I also hope to be able to share details of Sidney and Jovanas projects soon.

Trustees Update

To remind you of our trustees, following the AGM. Emily Bell was elected as a new trustee, and we welcome her into the group. All trustees from last year are carrying on, giving us six current trustees.

We have expressions of interest in our treasurer and secretary roles from two people. We're having a trustee meeting later in September, and I hope to report positive news after that!

Welcome to new members

I am always pleased to hear about new members joining us. I am happy to welcome them to our friendly supportive community, hoping they don't feel quite as lonely or isolated as they did before finding us.

Looking for Help

As you know we are a small charity, and we rely on people giving us their time to achieve all of our work. Our website has a page about how people with or without a connection to HSP could help the group: https://hspgroup.org/want-to-be-able-to-help-the-group/.

My HSP survey

As many know, I run an annual survey on my HSP blog. This year I am launching my 10th survey, and part of my analysis will look how peoples use of mobility aids changes over time. If you have taken part in any of my previous surveys I would appreciate your participation this year so I have more data. I am also looking at pain, and my 'life with HSP' section covers disclosure, funding, and menstrual health. Keep an eye out on my blog – I hope to launch in October, once I've got my questions finalised and translated into six other languages! https://hspjourney.blogspot.com/

Adam Lawrence

Editor's Column

A few months have gone by since I last put a newsletter together, and wow, they've certainly been an interesting few months. We've had the hottest and driest summer in history with my birthday actually recording the highest temperature ever in the UK. I hope you managed to find a way of keeping as comfortable as possible in the extreme heat, I know that most of us don't cope well with high temperatures. I enjoyed sitting in the shade in my back garden for long periods of time and found that a large bucket of water to immerse my feet in was beneficial. Like a lot of HSP'rs, I suffer with swollen feet in the summer months.

I know that Covid hasn't gone away and will probably never go away but it's been a huge relief to be able to get out and about again. As many of you know, I love live music and I've loved being able to regularly attend local events once again. I'm still enjoying hosting a weekly show on local radio and this together with organizing the Potato Pants Music Festival which you'll read about later in this newsletter, has kept me out of too much mischief

I mentioned in the last edition that on January 9th, my granddaughter Violet was born. Her brother is now nearly three and because they only live 5 houses along the road, I see plenty of them and it's lovely being involved in their lives and watching them learn new skills as they slowly grow up. My grandson loves jumping on my lap when I'm on either my wheelchair or scooter and having a ride. This is one of many unexpected positives I've discovered regarding owning a wheelchair.

Another activity that I've enjoyed over recent months is the monthly Zoom meeting I host for all members on the first Wednesday of every month. A highlight for me is the many new members we welcome who have never had the opportunity before to meet and chat with others who also have HSP. A huge variety of topics are covered and there are some who love to chat but also some who just like to listen and learn. These meetings were set up during the Covid lockdowns with the intention of keeping people in contact with one another while we were all shut in, but they've proved invaluable and will continue indefinitely.

I've decided that I'm going to try to do my bit for the environment. In June next year, the lease ends on my Motability car and I'm seriously thinking of not replacing it. I'll certainly see how I get on for a month or two without a car. I currently enjoy doing miles on my wheelchairs and mobility scooter and can get almost anywhere I want to, and my wife has a car, so I certainly won't be stranded at home. I'll also be in the region of £250 per month better off and this of course will pay for a taxi or two. I think that having a car has almost become a habit and I'm questioning whether I now really need one. What I will say is that having made use of the Motability scheme for the last 20 years, I think it's an incredible organisation and would strongly recommend it.

Talking of Motability, I always enjoy reading the Lifestyle magazine that is circulated to Motability customers. In the most recent edition, on page 44 there was an article about the cost-of-living crisis and tips on how to save money. One of the points raised was about insulation and it highlighted that people on disability benefits could be entitled to grants to cover costs of insulation. I investigated this and have recently had my loft re-insulated to current standards at no cost to me. If this is of interest, visit https://www.simpleenergyadvice.org.uk/grants

I have always funded my own wheelchairs and I now have excellent chairs that I wouldn't be without. A friend of mine recently suggested that I should make myself known at Wheelchair Services, she told me that it could prove useful to be on their system. I asked my GP to refer me, saying that I needed a better quality cushion. Many people won't realise this but pressure relieving wheelchair cushions can be well over £500. I got the appointment and Wheelchair Services couldn't have been more helpful. They've ordered me a quality cushion which I should have very soon. They also informed me that if I wasn't in possession of my own chair, they'd have ordered one for me, and they could even

provide the same chair that I own. If anyone is thinking of getting a quality chair, I would strongly recommend an appointment with Wheelchair Services, but my advice would be to do a bit of research first and make sure you know which chair you'd like and would best suit your requirements.

You'll notice that there's a social meeting for all members taking place at the Tally Ho Conference Centre in Birmingham on October 8th. Unfortunately, I won't be able to attend this because it clashes with a football match that I'll be attending. I'm still a season ticket holder at AFC Bournemouth and if you follow your football, you'll know that they're certainly currently delivering plenty of highs and lows. I love my football though and like to get full value out of my season ticket and never miss a home match. I will of course be attending the meeting in Ashburton that's taking place on November 5th and look forward to seeing friends there and meeting some new members. It's been far too long since we had a good get together in Ashburton.

Please keep the interesting articles coming in. I can't produce a newsletter if I have no content. Thank you to those who have contributed such interesting information to this issue.

I look forward to seeing many of you over the coming months. Remember to turn that thermostat down a degree or two but make sure you keep warm. A good fleece or blanket may prove to be a good investment this winter.

Ian Bennett

Amazing opportunity at The Calvert Trust

Some of you may remember our former Chairman David Pearce. On the front of the August 2006 newsletter David wrote an article about how much he enjoyed a stay with the Calvert Trust. For those of you who don't know, the Calvert Trust is an organisation with three locations around the UK, where they provide many exciting challenges for disabled people. These challenges include horse riding, kayaking, sailing, archery, cycling and abseiling to name but a few. I can remember David telling me what an incredible experience this was and he'd be delighted to know that some of our members have recently discovered for themselves how much fun and uplifting a Calvert trust break can be.

Sadly, David Pearce passed away in 2018 but he very generously left us some money in his will. Some of this was used for research but we wanted to use some for a purpose that we knew David would fully approve of. For this reason, we decided to pay half the cost of a Calvert Trust experience for any member. This is limited to one holiday per member every two years. We have allocated a certain amount of money for this and when it's gone, it's gone.

Please check out the Calvert Trust's website and if you like what you see, get yourself booked in. The HSP Group will refund half the cost.

For more information on this contact Ian Bennett

bravoechonovember@btinternet.com

Fundraising News

Thanks to all who have raised funds for us using Easyfundraising.

If you ever shop online and are interested in supporting the HSP charity, please register for this or get in touch. Use the following link and follow instructions:

https://www.easyfundraising.org.uk/causes/hspsupportgroup1/

We are also registered with Amazon Smile so you can now raise funds for the group when shopping at Amazon. To use this go to:

https://smile.amazon.co.uk/ch/1181539-0

and that will help you select the group as your charity. The difference from normal Amazon shopping is that you need to remember to do your shopping from https://smile.amazon.co.uk/ so that the donations come through.

Covid meant that we all stayed indoors for far too long. It is time to get out there again and think of ways to get some exercise and in doing so, maybe raise some funds for HSP. If you are running in an event for HSP, we will be very happy to provide you with an HSP Support Group running vest.

Ian Bennett

Fundraising for 2022.

Rosanna Grimwood hiking the Dales Way triggered contributions from her employer of £400. She has been raising money with her colleagues at work for a friend's daughter and KPMG offered to make a corresponding donation to a charity of their choosing.

Money was donated at funerals in memory of (Stella Hopkins, Phil Burton and Robert Cotton): £290

Donations from individuals include a collection at the Paisley Church of Scotland of £392. Individual donations came from others including Ian Rouse.

Fundraising efforts included came in a variety of forms.

Ray Greening holds a monthly music event in his local park playing soul jazz and funk music. He donates the proceedings to various charities and we received £685.

Estelle Hetherington is preparing to run the London Marathon and has already raised over £1,400.

Peter Bateman continues to raise money from collection boxes selling pens and keyrings and has sent £400.

Ian Bennett has run the brilliant Potato Pants music festival and raised £2,020

Well done to everyone and our heartfelt thanks for putting in the effort and for supporting our charity.

John Mason - Treasurer

HSP Group Grants

Funds are available for members to apply for financial assistance with the purchase of mobility aids or equipment that may improve quality of life or simply make life easier.

The maximum grant available is currently £1000. Completion of one year's membership is a requirement for applicants. If interested, please request a grant application form from the Secretary Dave Harris, details at the end of this newsletter. There is also an online form available via our website.

Members' Letters

A Disabled Holiday with a Difference!

I have discovered a holiday 'Gem' like no other. I have just been to Merton House Hotel in Ross-on-Wye, Herefordshire. If you are elderly with HSP, this is the place for you. Merton House is situated near the Forest of Dean and boasts stunning views over the Wye Valley. Its garden is beautiful and leads your eyes to the river which is readily accessible for mobility scooters and power chairs etc. Mobility scooters and other equipment are also available to use. They have thought of everything!

Gary enjoying the River Wye on his scooter

In addition to the wonderful surroundings the management organise trips, in most cases for a small charge, to interesting places in the locality using the accessible minibus, eg Abergavenny, Hereford Cathedral and town, Malvern and Weston-Super-Mare, etc. I am researching, at present, whether there are any accessible paths in the near-by Brecon Beacons, Black Mountains, or Symonds Yat areas.

I had a wet room on the ground floor which was perfect. There was also entertainment most evenings for those who like to indulge. The hotel offers half board, plus snacks and drinks at other times during the day, even night drinks at 9.00pm! – all included. They also serve up lovely three course meals, using local fresh produce; catering for special diets, if required. All the staff are so friendly and really look after you. Lastly, at an extra cost 'Door to Door' transport, accessible if needed, is available to and from your home.

Wow! What a place? It's a no brainer!

Gary Cliffe

Everyone can sing

According to Gareth Malone, the renowned choir master, everyone can sing which is something I hoped would be the case when Mum and I plucked up the courage to join our local Octagon Theatre choir group in June 2019.

We were concerned that previous school choir experience alone would not be sufficent. We were quickly assured that the choir was all about singing for pleasure! I am one of the youngest members and Mum and I have made great friends with lots of people.

The choir session lasts for two hours every Monday evening between 7pm and 9pm and there are roughly 30-40 members at each session. Our choir master, Adam, is also the theatre manager who is passionate about the choir and spreads his enthusiasm to us all; a multi-talented man who can sing, dance and accompanies us on the piano.

We sing a wide range of music, including West End musicals and the odd more challenging song in Latin or Italian! Prior to Covid, we were performing concerts annually on the theatre stage, – including being the backing singers for Blake, a classical British Vocal Group who undertook a concert at our theatre. Singing with a professional group was quite an experience.

Due to Covid, I had to sing courtesy of Zoom, from my own sitting room every Monday night for many months. I love singing but singing alone was very boring!

Finally, we are now back singing as a group and busy practising for our Christmas concert. I am looking forward to wearing our red and black coloured choir performance clothes again and an excuse for the hairdresser to pay an extra visit!

Joining a choir has really given me a much needed perspective to focus on not just in terms of meeting a new group of people but pushing me to learn to read music, improving my breathing control and speaking voice and hopefully my singing voice!

I would recommend it to anyone.

Phillipa Burrell

Another Disabled-friendly Holiday!

In early July I went on another trip; this time again with Limitless Travel. I had been with them before last year to Brighton and had a wonderful time. They are a disability specialist holiday company with fantastic carers and a tour manager. I joined their Dorset and Coast holiday this time, based in Bournemouth. We spent the first day in Bournemouth and visited the Russell Cotes Gallery and Museum, pier which overlooks

the golden sandy beach, before venturing in the town and gardens.

The next day the small group went to see Stonehenge in Wiltshire after each person was placed onto the fully accessible coach by a lift. Later, after spending some time there and lunch, we went to nearby Salisbury where we spent some time in the town and an evening meal in a restaurant.

Another day the group went to the seaside town of Swanage. We had the opportunity of seeing the town before boarding an accessible steam train along the Dorset coast, passing Corfe Castle and aspects of the Jurassic countryside.

Gary at Corfe Castle

Limitless take care of everything and is particularly useful for perhaps those without alternative help. The group quickly jelled, and it was so nice to meet others in similar circumstances and make new friends. I certainly plan to go with them again!

Gary Cliffe

Potato Pants Festival

The 2022 Potato Pants Music Festival took place on September 3rd at Cobham Sports and Social Club on the edge of Wimborne in Dorset. Live music started at 12.30 pm and continued throughout the day until 11.15pm. We were entertained by 12 acts, six of which were bands and six solo artists. There were actually 30 musicians entertaining us and they're all totally on board with what Potato Pants is all about and they don't charge a penny to perform. With this in mind, it would be lovely if we could repay them in other ways and at least give them a like on their Facebook pages, these 'likes' actually make a difference. Three stages were used throughout the day, two of which were outside. We used an inside stage after 9pm for the final two noisy bands in an attempt to keep the neighbours happy.

Amie Knight entertaining the crowds at Potato Pants

Food and drink were available throughout the day and there were plenty of activities to keep families happy. The club has a great playground for children that was made very good use of, and face painting proved to be popular, particularly amongst the youngsters.

As well as the music we held the usual Potato Pants races which, as always, were very well contested. We got band members to race each other, we had a couple of ladies races and even got the kids involved.

It was lovely to see so many people with HSP take the trouble to attend this year, some of whom travelled a considerable distance. I think it's great that festival guests see HSP affected people throughout the day. It gives a clear visual indication of what the Potato Pants Festival is all about. Some of my good friends with MS also attended and this is the reason that I use this venue. It's a very accessible site with disabled toilets and ramps allowing access to the hall and bar.

I've had some great feedback since the festival, people mainly saying how much they enjoyed the day and what a lovely atmosphere it was. I haven't done an exact count yet because there's still a couple of payments to come in, but we raised very close to £2000.

I'm already making plans for next years event.

Ian Bennett

Zoom Meetings

Family chat Zoom meeting Thursday 18th November 2021

The meetings committee have been wanting to get parents & carers of children, young people & dependant adults with HSP together for a long time. Being scattered throughout the UK, we understand that it's difficult to get everyone together in one place, what with travelling etc, it can be a challenge for even the most organised of families.

With this in mind, we decided, at very short notice, to arrange a zoom 'family chat meeting'. It was advertised about three days before on the hsp support group website https://hspgroup.org/hsp-support-group-meetings/

Hereditary spastic Paraplegia support for UK HSP'rs Facebook page https://www.facebook.com/groups/731239283741617/?ref=share

& sent to all members by the HSP Support Group e-mail facility.

We were pleased to welcome four people to the family chat & there were eight others that expressed interest in joining the chat, but couldn't make the November family chat because of work and other commitments.

One lady hadn't met any other HSP'rs. It was her first time & she appreciated the help, support and experience from other parents, plus sharing the experiences she had gained through her HSP journey.

Many subjects were covered including wheelchair services, personalising wheelchairs etc, social clinics, FES, suitable cars/mobility equipment, hsp clinics/consultants, plus obtaining the referrals/medical help needed.

All felt the meeting had been successful and were keen to meet again.

We hope to welcome you to the next one.

Della Brookman.

SPG 11 and SPG 15 Zoom Meeting 26th January 2022

We have a separate meeting for these types of HSP because, although they are very similar to each other, they are very different, in some ways, from other types of Hereditary Spastic Paraplegia, most (but not all) of those affected being young adults dependent upon their parents.

These two types of complex Hereditary Spastic Paraplegia are particularly rare and the few affected families are scattered across the country so Zoom gatherings work very well for us.

Seven people, both affected young people and parents, were able to come along and others dropped by to say 'Hello', even though they had other commitments that evening. We met new people and caught up with old acquaintances, chatting for over two hours, getting to know each other better and sharing experiences.

We talked about symptoms such as pain and the different medications people have been offered, though a number of people didn't experience pain along with the spasticity, which was good news. We discussed the various activities available and the limits imposed by fatigue. Some play wheelchair sports, even if they are not wheelchair users, while others feel sport isn't for them. We covered the impact covid has had on progression and mood. We talked about the variable provision of physiotherapy and also about the problems arising from continence issues. One family had found the Just Can't Wait Card (https://www.bladderandbowel.org/help-information/just-cant-wait-card/) to be helpful and many found carrying a radar key to be very useful (https://www.disabilityrightsuk.org/shop/official-and-only-genuine-radar-key). Some people have moved house and others have adapted their homes to ensure the accommodation, including the bathroom, is accessible.

We discussed the need to plan in great detail when travelling, whether in this country or

abroad, and the frustrations that can arise, even with the best of planning! Some had managed to fly, while others had restricted themselves to holidays in the UK because of the complexities of international travel. Even in this country people had found it difficult to locate accessible accommodation. The general sense was that everyone could do with a proper holiday!

Inevitably, we talked about PIP but it did seem as though most people were getting the right decision in the end. We also discussed research and selective dorsal rhizotomy, a surgical procedure to release spasticity, which we believe is not yet available in the UK for HSP.

Finally, the young people, themselves, are arranging to meet up through Facebook.

We plan to meet again on Zoom, so if you have SPG 11 or SPG 15 in your life, and would like to join us, please get in touch with me by email so that I can send you the joining details, when we have a date. I'd love to hear from you.

Hilary tohiti@btinternet.com

Zoom Meetings for all HSP'rs

First Wednesday of every month

These meetings began during lockdown because we felt that it was important to give people the opportunity to get together and keep in touch with one another.

I volunteered to host them and have really enjoyed doing so. Attendances vary from about a dozen people to 40 and these people are always spread all around the UK. Since lockdown attendances have understandably dropped a little but a wealth of information has been shared. The list of topics discussed is far too long to print, but mobility aids, disability benefits, exercises, holidays, different types of HSP, symptoms, HSP specialist locations, and medication are regularly discussed.

New friendships have also developed which is always a highlight for me and on a few occasions, we've had people attend who have never come across anyone else with HSP.

These meetings begin at 7pm and usually end at around 9pm but people are free to come and go as they want. We have people who love to talk, and we have others who love to listen and learn. Both types are very welcome at these meetings.

Invitations and reminders are sent out to members by email.

I look forward to seeing regulars and new faces at future meetings. If you'd like further information on these meetings you can contact me by email bravoechonovember@btinternet.com

Ian Bennett

Forthcoming Events

Social Day for Members

October 8th 11am – 3.30pm
Tally Ho Conference Centre, Birmingham

The South West

November 5th 2pm
The Dartmoor Lodge Hotel, Ashburton
Contact Ian Bennett: 07941 535 282

A meeting for all members

Simply a natter to catch up with old friends and maybe make some new ones
The first Wednesday of every month 7pm, online using Zoom
Zoom details are emailed to all members or
Contact Ian Bennett: 01202 849 391 or bravoechonovember@btinternet.com for info

Birmingham/West Midlands

November 26th 12.00pm – 3.30pm
pennycohen57@hotmail.com or june_masding@hotmail.co.uk for details

Colchester/Essex

October 16th 2.30pm – 5.00pm
Contact Hilary Croydon for further information Tel: 01284 728 242
tohiti@btinternet.com

Milford

Sunday November 20th 2pm – 5pm
The Clockhouse Milford
GU8 5EZ
Call Jane Bennett on: 020 8853 4089

New Members

We welcome the following new members:

Paul Groom Bromley	Balint Lazar Tonbridge	Tamsin Wright Lochwinnoch
Karl Ryder Nottingham	Robert Gall Plymouth	Rachael Brown Eastleigh
Ian WInton Wirral	Sue Hall Powys	Miranda Bedwin Sudbury
Martin Hall Isle of Lewis	Caroline Hill Cirencester	Mary Featherstone Barnet
Martin Bryant Ilfracombe	Karen Britton Redditch	Angus O'Donnell York
Paul O'Neil Manchester	Shanake Amarasinghe Croydon	Heather Shepherd Deal
Andrew Walker Crawley	Rachel Glover Cumbernauld	Peter Rawl London
Emily Bell Basingstoke	Emily Leivesley Haydock	Mike Featherstone Newcastle
Colin Atkinson Wallingford	Jeanie King Poulton Le Fylde	Stephen Alexander Arbroath

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Since our AGM we've had two online presentations

Here is a summary of them:

1) Overview of Benefits

Janet McBride from Citizens Advice (https://www.citizensadvice.org.uk/) gave an overview of the different types of benefits that those in the UK with HSP may be entitled to. You can watch this on our YouTube channel: https://www.youtube.com/watch?v=XgAImXb5YI0. Janet began by summarising the four main types of benefit which are likely to be relevant:

- Disability
- Sickness
- Low income
- Carer

Each of these is covered below. The general approach for these benefits is to begin your claim by telephone, so that the date you claim the benefit from is as early as possible. Using the telephone makes the start point the day you contact them rather than the date that they have finished processing your application.

You can check which benefits you may be entitled to using one of these tools before spending a long time filling in complex forms and attending appointments. Entitled to: https://www.entitledto.co.uk/ or turn to us: https://benefits-calculator.turn2us.org.uk/

You can get help from citizens advice on any of these. If you don't like the decision on benefits then you can challenge the decision - but challenges can be difficult to be agreed unless there is new compelling

evidence. You need to tell the benefit department if you have a change in circumstances. Further information can be found on https://www.citizensadvice.org.uk/.

Disability Benefits

The disability benefit is not means tested. The specific benefit you would apply for depends on your age. Those under 16 would apply for Disability Living Allowance (DLA), those in retirement would apply for the Attendance Allowance, with all others applying for Personal Independence Payment (PIP).

DLA is available for children who need more care than children who aren't disabled and/or who have difficulty moving around/safely compared with children who aren't disabled. Children must have been disabled for at least 3 months and are expected to remain so for at least another six months. There are two elements for DLA, a care element and a mobility element. There are different rates within each element, and you may get one or both elements, paid weekly. This benefit is available from the DWP: https://www.gov.uk/disability-living-allowance-children

PIP is available for adults who find everyday tasks hard, who have found these things hard for at least three months and are expected to find them hard for at least another nine months. Needs are assessed against 10 daily living different activities and two mobility activities. Each activity is scored, and there are thresholds for a 'standard' and 'enhanced' allowance. You may get either the daily living part and/or the mobility part, paid weekly. This benefit is available from the DWP: https://www.gov.uk/pip

Attendance Allowance is for people who need others to physically attend to them during the day and/or the night. There are two elements, the day element and/or the night element. This benefit does not cover mobility issues. Further details here: https://www.gov.uk/attendance-allowance

Sickness Benefits

If you are ill whilst you are employed you are likely to be able to get Statutory Sick Pay, otherwise the New-style Employment and Support Allowance (ESA) or New-style Job Seekers Allowance (JSA) are potentially available.

Statutory sick pay is payable to employees (i.e. not self employed) when you are sick for at least four days in a row and you have followed your employers rules. This is payable weekly up to 28 weeks. You may be entitled to contractual sick pay, so check with your employer if this is the case. Details here: https://www.gov.uk/statutory-sick-pay

New-style ESA is available if you are self employed or if you are still sick after your 28 weeks of statutory sick pay. You must have sufficient national insurance contributions. This is paid weekly. Details here https://www.gov.uk/guidance/new-style-employment-and-support-allowance

New-style JSA applies if you have decided that you are not likely to be able to return to your original job, but you are likely to return to work in a different role. You must have sufficient national insurance contributions. This is paid weekly. Details here: https://www.gov.uk/guidance/new-style-jobseekers-allowance

Low Income

Universal Credit is available if you are too ill to work and you don't have enough to live on. It is the main means tested benefit for people of working age. There are a number of elements to this benefit above the standard amount, including housing, children, childcare, sick or disabled and carer. There are a whole host of criteria which need to apply. If you are sick or disabled you may get more money, and you may not have to look for work whilst claiming this benefit. Details here: https://www.gov.uk/universal-credit

Pension Credit is for people who are above pension age and who dont have enough to live on. There are two parts, guarantee credit and savings credit (savings credit for people who reached state pension age before 6 Apr 2016). Claiming pension credit can increase the value of other benefits. Details here: https://www.gov.uk/pension-credit

Carers Allowance

This is available if you spend at least 35 hours a week caring for someone and you earn less than £132 a week after deductions. The person you are caring for must also be getting at least one of the specific benefits. If you care for someone for at least 20 hours a week you can get carers credits to help with

national insurance and allow you to claim some other benefits. This benefit is an income replacement benefit. You can only apply for one income replacement benefit, so for example you could not receive carers allowance at the same time as getting a state pension or contributory JSA/ESA. But, you may be able to get a premium added to other benefits. Details here: https://www.gov.uk/carers-allowance

2) The Molecular Basis of HSP

Prof Andrew Crosby and Dr Emma Baple from Exeter University gave an overview of the work that their team has been doing in recent years. The HSP support group had part-funded Olivia Rickman for her PhD studies, and this presentation was to report to members the outcomes of the research that we had funded. You can watch the presentation on our YouTube Channel:
https://www.youtube.com/watch?v=Mfk6qap2ric

Commonalities

They began by describing that their work covers more than just HSP, and that there is learning from different motor neuron disorders that helps improve the understanding of HSP, and similarly the work on HSP often helps understanding of other motor neuron disorders. Several of these motor neuron disorders (including HSP) affect the upper motor neurons, and there are a range of similarities in these conditions.

HSP genes

Their work has been looking at genes, with the human having some 22-25,000 genes, of which about 7,000 are understood. Genes code life, and their job is to make proteins, which then go on to build up life. Their team have discovered 16 genes which are responsible for HSP so far. Once identified these genes offer the potential for genetic testing for families and can give insights into how HSP works. HSP changes the genetic coding of the gene, which then affects how the protein is made. Their work then seeks to understand how the HSP affects the proteins, the role of the protein within the cell, and how the change made by HSP affects that role. With this they can find out what the motor neuron is supposed to be doing, and why it is not doing that with the HSP, which offer the potential to investigate options to intervene.

Genetic Testing

In England the genomic medicine service was recently launched, which allows whole genome sequencing. This sequencing takes a matter of days to give the whole genetic sequence. There are two panels of genes that are tested against for HSP, there is a panel with 76 genes currently for adults and 70 genes currently for children. Some genetic conditions have genetic overlap with multiple conditions, and there is a broader panel of neurodegenerative conditions which can be used, which tests against 96 genes, some of which are HSP genes.

Despite knowing about all of the HSP genes discovered so far, a genetic diagnosis of HSP can only be given to about half of people, which indicates that there are still a lot more HSP genes to be discovered. It is understood that the majority of the more common genes for HSP have been identified, which means that those genes which have not yet been identified will each affect a relatively small number of people.

Commonalities between HSP types

One of the key questions is why are there so many different genes which cause HSP - in more detail do these genes all have unrelated functions or roles or do these genes work together in common pathways within the cell. It is thought that the common pathways are more likely, so that any of the HSP genes can affect one of the common pathways, giving rise to HSP. Essentially the symptoms of HSP arise because of a problem in the common pathway. The main issue with these studies is that the function of many of the genes understood to cause HSP are not known or not well known, so identifying the common pathway is difficult.

Two of the HSP genes discovered by the team are in pathways which are well understood, so this gives a good link between HSP and these pathways, and allows understanding of HSP on the pathways to be

explored. One of these is CYP7B1 on the cholesterol pathway and the other is EPT1 on the Kennedy pathway. Both pathways are to do with processing fats and cholesterols, which show that these fats and cholesterols are important for HSP.

The team then looked at the other genes which have been associated with HSP to examine if these are associated with those pathways. There is some evidence which links some of these genes to these pathways. One of their recently identified HSP genes (TMEM63C) was also found to be at a key location for the fat processing routine.

Future work

When looking at the plans for future studies they are focussing on two areas. One area is to continue to find more HSP genes to understand more about the pathways and how they are affected with HSP. The other area is to look at the fat processing pathways and to understand what happens when the pathway is disrupted by HSP. Whilst these pathways are understood to some degree, the differences between how they work within different cell types is not so well known. This area is challenging and new processes have been developed for the analysis work. They have been creating cell models for HSP and editing the genes to take the gene out. This then allows the cell to work in a similar way to how they would work in a person, and this then allows the cell functions and associated impairments to be studied.

The team are using this technique to be able to compare different types of HSP to be able to examine similarities and differences in the fat processing pathways to be able to confirm which HSP genes are involved in these common pathways.

Useful Contacts

	Email	Telephone No:
Adam Lawrence - Chairman 18 Mayflower Court, Staple Hill, Bristol, BS16 5FD	**adam@idios.co.uk**	07834 505 161
David Harris – Secretary 18 Lodmoor Avenue, Weymouth, Dorset, DT3 5AF	**dave@vadcar.org.uk**	01305 772 286
John Mason - Treasurer 18 Sandringham Road, Trowbridge, BA14 0JU	**john@jrmweb.uk**	01225 761 788
Mitesh Patel – Trustee/Membership Sec	**miteshpatel59@hotmail.com**	
Ian Bennett – Newsletter Editor & Devon host 37 Wimborne Road West, Wimborne, Dorset BH21 2DQ	**bravoechonovember@btinternet.com**	01202 849 391
Jane Bennett – South / South East meetings host	**luckyjane82@hotmail.com**	020 8853 4089
Della Brookman – Herts meetings host	**della_brookman@msn.com**	07710 637 941
Penny Cohen – Birmingham meetings host	**pennycohen57@hotmail.com**	07818 288 738
June Masding – Birmingham meetings host	**june_masding@hotmail.co.uk**	01214 445 095
Mike Cain – Trustee & Northern meetings host	**michaelcain123456@yahoo.com**	0161 456 7531
Hilary Croydon - Essex meetings host	**tohiti@btinternet.com**	01284 728 242
Barbara Jones – Norfolk meetings host		01603 423 267
Kevin Mills – Wales meetings host	**kevinmills944@gmail.com**	01874 622 727